

CLEFT LIP — CLEFT PALATE

ORGANIZATIONAL GUIDELINES

Organizational Guidelines represent the minimum requirements for providing care for individuals with cleft lip / left palate. Care and treatment should be provided in a manner that includes adherence to and consistency with each of the following guidelines.

CRS Enrollment:

Patients diagnosed with cleft lip/cleft palate and craniofacial anomalies must be enrolled at a site with a cleft lip/cleft palate and craniofacial anomalies clinic.

Interdisciplinary Team Membership:

The following team members must be available to attend clinics and team conferences, review patient information, determine the need to see the patients at a clinic site and be available for inpatient consultation or coordinate care with inpatient staff at CRS contracted hospitals. It may not be necessary for each member to see the patient at each visit. One team member can fill more than one role if properly trained.

- Audiologist
- Child Life Specialist
- Child Psychologist
- CRS Member / caregiver
- Dentist
- Educator
- Genetic Counselor (Optional)
- Geneticist
- Nutritionist
- Oral and Maxillofacial Surgeon
- Orthodontist
- Otolaryngologist
- PCP (Invited)
- Pediatrician
- Plastic Surgeon
- RN Nurse Coordinator
- Social Worker
- Speech Therapist

Consultative Personnel:

The clinic must have access for consultation to specialists as identified by the Team.

Outreach Clinics:

Outreach Clinics are designed to provide a limited specific set of services including evaluation, monitoring and treatment in settings closer to the family than a clinic. Major treatment plan changes must be communicated to the clinic. Members with cleft lip / cleft palate and craniofacial anomalies may be seen in related specialty field clinics such as plastic surgery or nutrition clinics. Field clinic records must be provided to the clinic serving the member.

Community-Based Services:

Community-based services means all local services including provider agencies, schools, private physician offices, hospitals, and / or any other local setting. The following community based services may be provided from a community-based setting:

- Lab Services
- Pharmacy Services
- Speech Therapy
- General Dentistry (The dental services associated with cleft lip / cleft palate and craniofacial anomalies are specialized; they need to be provided at the clinic site or in private dental offices with the Interdisciplinary Team involved).

Facilities and Services:

- Age-appropriate setting for all patients
- Defined age-appropriate services, i.e., Pediatrics, Adolescent Medicine, and/or Internal Medicine
- Pediatric and / or Adult Intensive Care Units appropriate to the age and complexity of the medical condition as determined by the orthopedic surgeon with medical consultation as needed
- Social Work Department
- Child Life Services
- Physical Therapy
- General Dentistry- Oral and Maxillofacial Surgery, Orthodontic, and Prosthodontic pediatric services available
- Identified clinic area for outpatient services
- X-ray services
- Equipment and expertise to measure height and weight

- Access to the pharmacy

Team/Staff Meetings:

Team and staff meetings will be held based on the age of the patient and their diagnosis. At a minimum the following will occur:

1. Interdisciplinary Team Meetings . Evaluate patient at regularly scheduled intervals, the frequency and specific content of those evaluations being determined by the condition and needs of the patient and family. Hold regularly scheduled face-to-face meetings for discussion of findings, treatment planning, and recommendations for each patient. Develop a longitudinal treatment plan for each patient that is modified as necessitated by craniofacial growth and development, treatment outcomes, and therapeutic advances. CRS sites are encouraged to perform periodic chart reviews with documentation to ensure that all patients are reviewed and planned appropriately, and according to, their underlying condition.
2. Staff meetings once a year to focus on issues of clinic patient care and clinic administration.

Lead Physician Specialists:

Qualifications: The Lead Physician Specialist should be a Team Member with experience and expertise in serving members with cleft lip/cleft palate and craniofacial anomalies.

GUIDELINES FOR PATIENT SERVICES, EVALUATION, AND MONITORING FOR CLEFT LIP/CLEFT PALATE

The purpose of these guidelines is to promote a uniform level of care at CRS Clinics for members with cleft lip / cleft palate and craniofacial anomalies and to provide a general framework for excellence in patient care. Their relevance to specific situations will depend on individual variations in clinical course and professional judgment, growth and development, and treatment techniques. In addition, this document should serve as an outline to assess programs, secure resources needed to enhance patient care and education, and guide the future development of treatments for patients with cleft lip / left palate and craniofacial anomalies.

Diagnosis & Treatment:

Goal: To provide accurate and timely diagnosis of patients with cleft lip/cleft palate and craniofacial anomalies.

Goal: To habilitate the patient through appropriately timed multidisciplinary interventions and monitor treatment progress and provide proactive treatment as appropriate.

Infancy:

- Consultation with plastic surgeon

- Consultation with pediatrician (Peds Screening)
- Contact made with Orofacial Team Coordinator
- Contact made by Social Services
- Evaluation by a Feeding specialist
- Contact with other specialty as necessary
- Visit with plastic surgeon
- Otolaryngology screening
- Audiology screening
- Follow-up with pediatrician (Peds Screening)
- Orthodontics for palatal control device if required
- Contact with other specialty as necessary
- Consultation with a geneticist
- Repair cleft lip
- Audiology follow-up
- Social Service Follow-up
- Pediatrician / PCP Follow-up
- Contact with other specialty as necessary

Age 12 to 18 months:

- Cleft palate repair or when determined as necessary
- PE Tube placement or evaluation
- Speech / language evaluation
- Developmental Screening
- Pediatric dentist for oral examination, preventive education/procedures, speech/language evaluation
- Contact with other specialty as necessary

Age 2 to 3 years:

- Cleft palate repair or when determined as necessary
- PE Tube placement or evaluation
- Speech / language evaluation
- Developmental Screening
- Pediatric dentist for oral examination, preventive education/procedures, speech/language evaluation

- Contact with other specialty as necessary

Age 4 to 6 years:

- Evaluation for VPI (velopharyngeal incompetence)
- Surgical procedures as needed such as pharyngeal flap or palatal lift
- Orthodontia-dental/facial orthodontia treatment initiation
- Evaluation by craniofacial team for future orthognathic surgery
- Screening for developmental and special education needs and referral as appropriate
- Contact with other specialty as necessary

Age 6 to 9 years:

- Screening for self esteem and teasing issues and referral to psychology as needed
- Contact with other specialty as necessary

Age 9 to 11 years:

- Bone grafting of alveolar cleft
- Contact with other specialty as necessary

Age 11 to 18 years:

- Orthodontia (alveolar ridge notch & CP palate patients only)
- Prosthodontic Dentistry
- Lip revision / rhinoplasty
- Orthognathic surgical procedures with post op evaluation of VP function and articulation by speech pathologist
- Contact with other specialty as necessary

Children Entering System at Older Ages:

For patients enrolled in CRS after early childhood, the treatment parameters will be modified as appropriate for the patient's individual needs.

Transition Planning:

Planning for transition to adulthood should begin at age 14 years and continue until age 21 years.

Ongoing Patient Evaluation and Monitoring:

Goal: To anticipate and treat psychosocial problems and management of the condition.

Psychosocial support with periodic assessment of patient and family needs. This can be performed by various specialists with referrals as indicated.

References:

Parameters for Evaluation and Treatment of Patients with Cleft Lip/Palate or Other Craniofacial Anomalies. Official Publication of the American Cleft Palate-Craniofacial Association. Revised Edition October 2004. <http://www.acpa-cpf.org/teamcare/parameters04rev.pdf>

Annex 1: European Collaboration on Craniofacial Anomalies (EUROCRAN). 2004
<http://www.eurocran.org/content.asp?contentID=105&sid=211448>

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